



Briefing for the Public Petitions Committee

Petition Number: [PE1499](#)

Main Petitioner: Robert Watson on behalf of CHAS Young Adult Council (YAC)

Subject: Calls on the Scottish Parliament to urge the Scottish Government to work with charities to help create suitable respite facilities to support younger (aged between 21 and 45) disabled adults with life shortening conditions. Together, they should be working with other hospices and care providers to see if some could provide facilities for younger adults, or better still they should be committing funds towards creating new purpose built facilities for this age group.

Background

Respite care is a service intended to benefit a carer and the person he or she cares for by providing a short break from caring tasks¹. Young people aged between 15 and 25 years old make up 13% of the Scottish population but only a small number of these will have palliative care needs².

The [Scottish Partnership for Palliative Care](#) is an umbrella organisation which supports and contributes to the development and strategic direction of palliative care in Scotland. Hospice services in Scotland for children and young people who have life-shortening conditions for which there is no known cure are provided by the charity [Children's Hospice Association Scotland](#) (CHAS). CHAS runs two children's hospices, Rachel House in Kinross and Robin House in Balloch, and a home care service called CHAS at Home. In May 2013 CHAS announced that it will no longer be able to provide services for young people aged 21 or above³ from 2016. There are a number of hospices and NHS specialist palliative care units in Scotland which provide in-patient, day care and home care services for adults.

In its report [Palliative Care for Young People Aged 13 – 24](#) the Joint Working Party on Palliative Care for Adolescents and Young Adults noted that:

¹ [Respite Care Scotland 2013](#) reported that in 2012/13 there were 205,810 overnight and daytime respite weeks provided in Scotland for a variety of conditions. Of these 23,910 were provided for people aged between 0 and 17 years and 75,170 were for people aged between 18 and 64 years.

² [Recommendations for service configurations for adolescents and young adults with palliative and end of life care needs](#)

³Third Force News (2013) [Children's hospice charity sets age limit](#)

“adequate provision of respite care is essential to minimise the effects of illness/disability and improve quality of life. Yet for young people over the age of 18, there is very little suitable respite provision, whether it is a local short break, in the home or a longer period away from home.....This group of young people is very vulnerable and yet they are often moved into environments where they are side by side with adults with learning difficulties and mental health problems. This is not in their best interest; and appropriate respite provision is a major gap in services. This is particularly significant when the young person’s cognitive age is below that of an adult, where perhaps a child-oriented environment would be more acceptable to the family. Most young people are still cared for by their parents in the family home....Many adult hospices / palliative care services say that they are willing to accept young people. A few have accepted and satisfactorily managed a small number of young people (1 or 2 per year), mainly in the terminal stages. But they have experienced problems with more active young people attending for respite (e.g. young men with muscular dystrophy), especially in relation to independence, personal care and embarrassment, issues around sexuality and social activities.”⁴ (p33)

There does not appear to have been any work focused on the respite care needs for people aged between the ages of 24 and 45, which is the upper age proposed by the petitioner.

Scottish Government Action

The Scottish Government published [Living and Dying Well](#) a national action plan for palliative and end of life care in 2008⁵. This aimed to ensure a cohesive and consistent approach to palliative and end of life care based on clinical need regardless of diagnosis or of age.

[Living and Dying Well: Building on Progress](#) sets out the next phase of actions required by NHS Boards working with stakeholders. It reports the work of the short-life working group 6 which considered the service configurations necessary to meet the palliative care needs of adolescents and young adults.

In the report [Recommendations for service configurations for adolescents and young adults with palliative and end of life care needs](#) (2010) the short-life working group highlighted the importance of “facilitated access to planned short breaks at facilities where there is very good holistic nursing and medical care, so as to provide respite for adolescents and young adults with illnesses with long disease trajectories, and their families”⁶ (p13).

The Scottish Government will shortly be carrying out a review of a sample of local authorities (with partners) to assess progress with support to carers and

⁴<http://www.palliativecarescotland.org.uk/content/publications/PalliativeCareforYoungPeopleaged13-24.pdf>

⁵<http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>

⁶<http://www.scotland.gov.uk/Resource/Doc/924/0105556.pdf>

those they care for. This review will include questions on short breaks/respice, including in relation to young adults⁷.

In November 2012 the Scottish Government published a [Framework for the Delivery of Palliative Care for Children and Young People in Scotland](#)⁸. This framework aims to ensure that there are recognised pathways for palliative care from the point of diagnosis. In relation to transition it states that health boards should develop local pathways for transition of young people with palliative care needs to appropriate adult services.

In July 2010, the Scottish Government announced funding of £1 million per year over five years to support the provision of additional short breaks and respice care⁹. The [Short Breaks Fund](#) is open to voluntary sector organisations who can apply for grants between £5,000 to £50,000.

Scottish Parliament Action

The Public Petitions Committee is currently considering [PE01471: Young People's Hospital Wards](#) which calls on the Scottish Parliament to urge the Scottish Government to establish specific young people's wards or rooms in hospitals for adolescents, and to ensure that staff receive adequate training to support young people's mental and emotional needs in hospital.

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12 November 2013

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⁷ Scottish Government personal correspondence 13 November 2013

⁸ <http://www.scotland.gov.uk/Resource/0040/00408254.pdf>

⁹ <http://sharedcarescotland.org.uk/short-breaks-fund.html>